

# Conversations with Patient Advocates: Ron Hollander, president of INCA

Ron Hollander, president of the International Neuroendocrine Cancer Alliance, talks to us about patient advocacy.

Nov 10, 2017

We believe we can make a greater difference through collaboration. That is why we are excited to introduce a new series – called “Novartis Connects: Conversations with Patient Advocates” – that will showcase stories from many of the patient advocacy groups working with Novartis. These organizations are helping us connect with the cancer community on a more personal level so we can better understand and meet patients’ needs.



Ron Hollander, president of the International Neuroendocrine Cancer Alliance

November 10 is World NET Cancer Day, dedicated to raising awareness of neuroendocrine tumor (NET) cancers. We recently spoke with Ron Hollander, president of the International Neuroendocrine Cancer Alliance (INCA) and executive director of the Neuroendocrine Tumor (NET) Research Foundation, who told us about his work and what sparked his passion for patient advocacy. He is stepping down as executive director of the NET Research Foundation this month after having served six successful years in this role.

We envision a world where all neuroendocrine cancer patients have access to a timely diagnosis, the best care, and ultimately a cure, no matter where in the world they live.

**Ron Hollander**, president of INCA

## How did you first become a patient advocate?

Hollander: I have been in healthcare and human services for many years, working especially with hospitals on issues of access and research. I’ve also had experience with academic work, but I missed the mission-centric vision of advocacy. When I met some people involved in the NET Research Foundation, I was struck by the absence of public information about NET cancers, and the lack of research being done to learn more about these tumors. After meeting some incredible members of the community, including patients, doctors and researchers – who are all very passionate – I was inspired to join the NET Research Foundation in 2012. The following year, the NET Research Foundation was invited to join INCA and I’ve been working with both organizations ever since.

## What is the mission of INCA?

Hollander: Our mission is to be the global advocate for neuroendocrine cancer patients. We envision a world where all neuroendocrine cancer patients have access to a timely diagnosis, the best care, and ultimately a cure, no matter where in the world they live.

## **What is INCA currently focused on?**

Hollander: Right now, we're gearing up for World NET Cancer Day, which is November 10. The theme this year is "Let's Talk About NETs," with the goal of raising awareness of neuroendocrine cancers at an international level. This year's focus is on talking about unmet needs, and we're aiming to expand participation beyond membership groups and nations to patients, researchers and others in countries around the world.

## **How can people support INCA's work?**

Hollander: We would like to get more countries around the world involved to help ensure that the voice of NET cancer patients is heard. Awareness is key because NET cancers aren't well understood, and patients are frequently misdiagnosed and treated for something they don't have. We encourage those who wish to support our efforts to get involved in our "Let's Talk About NETs" campaign.

Additionally, many of our organizations are volunteer-driven, so we encourage people to get involved on the local level. They can find the INCA members listing on our website online and discover ways to support their local organization on their respective sites.

## **What gives you hope?**

Hollander: The NET cancer community is a very special community. These types of cancers aren't well known or understood, but when patients meet each other, they make a real connection. They share information and want to help each other. There's also a strong sense of camaraderie among NET specialists from different institutions and localities. Working with this passionate community gives me a lot of hope and is very inspiring.

*Novartis provides funding to INCA and the Neuroendocrine Tumor Research Foundation. Hollander was not compensated for sharing his story, and all opinions are his own.*

Ron Hollander, president of the International Neuroendocrine Cancer Alliance, shares his patient advocacy story. #NETCancer

## **Looking for more information about INCA?**

INCA is a US-based nonprofit organization that provides patient education, support and information on neuroendocrine cancers. Its members span 17 countries and four continents.

[Learn more](#)

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